

Exploring Health Literacy among Adults with Hidradenitis Suppurativa

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Keywords

Hidradenitis suppurativa · Acne inversa · Health literacy · Awareness · Health education

Abstract

Introduction: Health literacy plays an important role in the management of chronic and debilitating skin diseases like hidradenitis suppurativa (HS). Adequate health literacy empowers patients to understand their disease, manage it effectively, and make informed decisions about their health. Exploring the interplay between health literacy and HS is essential to improve healthcare outcomes in this population. This study aimed to assess the prevalence of limited health literacy among HS patients and its associated factors which has never been studied before. **Methods:** In this epidemiological cross-sectional study, data were collected via a population-wide survey within the Lifelines Cohort Study in the Netherlands. Health literacy of participants with HS was compared to non-HS controls. The health literacy was measured using six validated questions covering functional, communicative, and critical health literacy. Associations between the characteristics of the HS group and limited health literacy were examined. **Results:** Out of 56,084 adult respondents, 1,156 participants with HS were identified. The prevalence of limited functional health literacy was 24.5% in the non-HS group and 26.4% in the HS group. Our findings indicate that limited health literacy among HS patients is associated with higher body mass index (BMI) (26.9 vs. 25.8) (OR: 0.969, 95% CI: 0.941–0.998), lower education level (34.5% vs.

19.9%) (OR: 0.495, 95% CI: 0.350–0.701), lower socioeconomic status (–0.68 vs. –0.58) (OR: 1.194, 95% CI: 1.029–1.386), and more severe disease stage according to the Hurley stage (33.0% vs. 25.8%) (OR: 1.400, 95% CI: 1.005–1.952). **Conclusions:** Our study highlights the importance of addressing health literacy in HS patients, given the high prevalence of limited health literacy among this group and associations with higher BMI and more severe disease stage. Limited health literacy may contribute to poorer health outcomes, suboptimal healthcare utilization, elevated healthcare costs, and health disparities. Targeted interventions to improve health literacy could enhance care quality and outcomes for HS patients.

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Plain Language Summary

Health literacy, or how well people understand and use health information, is crucial for managing chronic skin conditions like hidradenitis suppurativa (HS). HS is a common and often painful skin disease that causes bumps in the body folds. Often, oral and written information is provided about the disease, its treatment and lifestyle modifications. This study, from the Netherlands, aimed to find out how common it is for people with HS to have trouble with health literacy and what factors might be linked to this. For this study, we used a large database called Lifelines, that previously has been set up in the Northern Netherlands. In this Lifelines database, there is a lot of information available about the participants, which can be used for

research. We have used information from over 56,000 adults, including 1,156 with HS. We found that about a quarter of both the HS group and those without HS had limited health literacy, meaning they may struggle to understand health information. Those HS patients with limited health literacy tended to have higher body mass index, lower education levels and socioeconomic status, and more severe HS. Improving health literacy among HS patients could lead to better health outcomes, lower healthcare costs, and reduce health inequalities. So, it is important to find ways to help HS patients understand and use health information to improve their care and overall well-being.

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Introduction

The debilitating and chronic nature of hidradenitis suppurativa (HS), an inflammatory skin disease, manifests through recurrent painful abscesses, nodules, and sinus tract formation. HS is associated with smoking, obesity, and several inflammatory and metabolic comorbidities [1, 2]. The disease is accompanied by both physical and psychological symptoms, significantly impairing quality of life. The impact on quality of life might be caused by the uncomfortable symptoms of the disease itself, such as pain, pruritus, suppuration, and malodour. However, patients often also deal with depression, shame, fear of stigmatization, and problems with intimacy, which can eventually lead to isolation [3–5]. HS is a common skin disorder, affecting approximately 1% of the global population [6]. Despite its common occurrence, HS patients face a significant diagnostic delay, averaging 7–10 years, during which the disease can progress [7].

In recent years, patients have become increasingly responsible for their own health and healthcare, due to a shift from the patient as a passive recipient of healthcare to a more actively involved participant [8]. Nowadays, self-management is an essential part of healthcare, particularly for chronic diseases such as HS [9]. Patients with limited health literacy often encounter difficulties in self-management, leading to poorer health outcomes and increased utilization of healthcare services [10–13]. Health literacy, defined as “the cognitive and social skills determining the motivation and ability of individuals to access, comprehend and utilize information in ways that promote and sustain good health,” influences health behaviours and disease management. A widely cited health literacy model proposed by Nutbeam is considered useful for analysing the health literacy skills needed in various health situations [14]. Based on Nutbeam’s model of health literacy, three

types can be distinguished: functional (basic reading and writing skills), communicative (the ability to extract and apply information from different sources), and critical health literacy (the capacity to critically analyse information for greater control over life events and situations) [15, 16]. Limited health literacy is associated with decreased medication adherence, increased hospitalization rates, and even elevated mortality [17–19].

In HS, adequate health literacy would be of great importance in several aspects of the disease. Often, oral and written information is provided not only about the disease and its treatment but also about lifestyle modifications, including weight loss, smoking cessation, reducing skin friction, and stress management. Surveys conducted among HS patients have already revealed challenges in effectively managing the disease, comprehending the array of treatment options, and participating in shared decision-making [20, 21]. Several studies have shown an association between HS and lower socioeconomic status (SES); however, SES does not directly impact health [22, 23]. Health literacy is recognized as a mediator between SES and health [24].

Enhancing our understanding of the interplay between health literacy and HS is helpful in developing strategies to deliver effective healthcare, which is an important step in improving HS outcomes. Hence, studies on health literacy have not been conducted in this specific patient group. Therefore, we aimed to assess the prevalence of limited health literacy among HS patients and evaluated its associated factors.

Methods

Study Design

In this epidemiological, cross-sectional study, data were obtained from the Lifelines Cohort study. Lifelines is a multidisciplinary prospective population-based cohort study examining the health and health-related behaviours of 167,729 persons living in the North of the Netherlands [25]. It employs a broad range of investigative procedures in assessing the biomedical, socio-demographic, behavioural, physical, and psychological factors contributing to the health and disease of the general population, with a particular focus on multimorbidity and complex genetics. The Lifelines Cohort Study was conducted in accordance with the principles of the Declaration of Helsinki and the research code of the University Medical Center Groningen, the Netherlands. All participants provided written informed consent. The Lifelines protocol was approved by the University Medical Center Groningen (UMCG) Medical Ethical Committee under number 2007/152.

Participants with HS

Participants with HS were included if they were 18 years or older and had a diagnosis of HS according to the Skin Conditions questionnaire. This digital add-on HS questionnaire was sent out to all participants between February and May 2020 to identify participants with HS [22]. Participants were ascertained to the HS group when they answered positively the question (i) “Did you ever (during your life) get the diagnosis HS?” or to the two questions for self-diagnosing HS: (ii) “Do you have painful, recurring abscesses or boils in your armpits, groin, buttocks, or on other locations, as seen in the images below?” and (iii) “Did you have at least two outbreaks of abscesses or boils within a period of 6 months?”. The latter two questions have been validated in the HS cohort with positive predictive values of 85% and 96%, respectively [26, 27]. To assess the self-reported presence and stage of HS, images of HS lesions corresponding with the Hurley stages were additionally shown to the participants. More information regarding the study design can be found in the supplemental material (see online suppl. Methods; Fig. 1; for all online suppl. material, see <https://doi.org/10.1159/000543286>).

Measurements

Health Literacy

Health literacy was measured using self-reported responses to a set of six questions. Functional health literacy was assessed by three validated questions from Chew et al. [28]: (i) “How often do you have trouble understanding your medical situation because you have difficulty with the written information?”; (2) “How sure are you of yourself when you fill out medical forms?”; and (3) “How often does someone help you with reading information materials from the hospital or another healthcare provider?”.

Participants provided responses to these questions on a Likert scale from 1 (never/not at all) to 5 (always/very). The scores of the first and third questions were reversed. The sum of all scores resulted in a health literacy scale ranging from 3 to 15, where higher scores indicate higher health literacy levels. Subsequently, this score was dichotomized as either low (3–12) or adequate health literacy (13–15). This cutoff point was used in previous studies and leads to comparable percentages of low and adequate health literacy in large-scale health literacy surveys in the Netherlands [29].

Communicative and critical health literacy were measured by three statements derived from the validated Dutch Functional Communicative and Critical Health Literacy questionnaire [30]: (1) “I talk to other people about the problems/complaints for which I receive help or treatment.”; (2) “I collect information about the problems/

complaints for which I receive help.”; (3) “I collect information to be able to make decisions related to my health.”

Participants indicated their agreement with these statements on a Likert scale from 1 (never) to 5 (always), with a higher score indicating higher health literacy. These statements served as an explorative measure of communicative (first two questions) and critical (third question) health literacy, given the absence of a developed sum score for these aspects in existing literature.

Patient Characteristics

Sex, age, smoking status, body mass index (BMI), and education were extracted from the baseline assessment. Smoking status was categorized into nonsmokers, current, and ex-smokers. Education was categorized as low (no education or primary education), medium, and high (higher vocational education or university) according to international standards [31]. Socioeconomic status was determined by the Statistics Netherlands (a Dutch governmental institution that gathers statistical information about the Netherlands), based on inhabitants’ educational level, income, and job prospective (–8 to +3), where lower scores represent a lower socioeconomic status. Disease characteristics such as Hurley stage (categorized as Hurley I, II, or III) and age of HS onset were included.

Statistical Analysis

Descriptive statistics were used to characterize the included patients. Categorical data were presented using frequency distribution, while continuous data were presented as median (interquartile range) or mean (standard deviation) where appropriate. To maintain the anonymity of the Lifelines participants, frequencies below $n = 10$ were noted as $n < 10$ ($<x\%$, using 10 as the numerator). Additionally, missing cases are noted as NR and are not reported in the descriptive notes when $n < 10$. Unpaired t tests or Mann-Whitney U tests assessed group differences for continuous variables based on distribution. Chi-square tests or Fisher’s exact tests were used for categorical variables. Univariable and multivariable logistic regression analyses assessed the association between patient characteristics and low or adequate health literacy. Multivariable analyses were adjusted for age, sex, and BMI. For the univariable regression, the forced enter selection procedure was used, and for the multivariable regression, the backward elimination procedure was used. Associations were reported using odds ratios (ORs) with a 95% confidence interval (CI). Two-sided p values ≤ 0.05 were considered statistically significant. Statistical analyses were performed using SPSS Statistics 28.0 (2021) [32].

Table 1. Characteristics of the total study population

	Total, <i>n</i> (%) (<i>n</i> = 56,084)	HS group, <i>n</i> (%) (<i>n</i> = 1,156)	Non-HS group, <i>n</i> (%) (<i>n</i> = 54,928)
Functional HL			
Sex			
Female, <i>n</i> (%)	33,753 (60.2)	850 (73.5)	32,903 (59.9)
Male, <i>n</i> (%)	22,331 (39.8)	306 (26.5)	22,025 (40.1)
Age, median [IQR], years	56.0 [48.0–64.0]	52.0 [44.0–59.0]	56.0 [48.0–64.0]
BMI, median [IQR]	25.3 [23.1–28.1]	26.2 [23.6–29.8]	25.3 [25.3–28.0]
Missing, <i>n</i>	15	0	15
Education			
Low, <i>n</i> (%)	14,487 (26.3)	278 (24.5)	14,209 (26.3)
Intermediate, <i>n</i> (%)	21,527 (39.1)	486 (42.8)	21,041 (39.0)
High, <i>n</i> (%)	19,089 (34.6)	371 (32.7)	18,718 (34.7)
Missing, <i>n</i>	981	21	960
Socioeconomic status, median [IQR]	–0.57 [–1.19±0.17]	–0.61 [–1.29±0.12]	–0.57 [–1.18±0.17]
Missing, <i>n</i>	7,188	139	7,049
Help with reading information			
Never, <i>n</i> (%)	37,036 (82.0)	675 (76.6)	36,361 (82.1)
Occasionally, <i>n</i> (%)	6,066 (13.4)	145 (16.5)	5,921 (13.4)
Sometimes, <i>n</i> (%)	1,484 (3.3)	35 (4.0)	1,449 (3.3)
Often, <i>n</i> (%)	534 (1.2)	24 (2.7)	510 (1.2)
Always, <i>n</i> (%)	73 (0.2)	<10 (<x%)	71 (0.2)
Missing, <i>n</i>	10,891	NR	10,616
How sure fill out medical forms			
Not at all, <i>n</i> (%)	829 (1.8)	14 (1.6)	815 (1.8)
A little bit, <i>n</i> (%)	1,281 (2.8)	23 (2.6)	1,258 (2.8)
Somewhat, <i>n</i> (%)	4,559 (10.1)	102 (11.6)	4,457 (10.1)
Fairly, <i>n</i> (%)	25,769 (57.0)	518 (58.8)	25,251 (57.0)
Very much, <i>n</i> (%)	12,741 (28.2)	224 (25.4)	12,517 (28.3)
Missing, <i>n</i>	10,905	275	10,630
Trouble understanding medical situation			
Never, <i>n</i> (%)	30,665 (67.9)	574 (65.2)	30,091 (67.9)
Occasionally, <i>n</i> (%)	9,409 (20.8)	206 (23.4)	9,203 (20.8)
Sometimes, <i>n</i> (%)	4,665 (10.3)	93 (10.6)	4,572 (10.3)
Often, <i>n</i> (%)	343 (0.8)	<10 (<x%)	337 (0.8)
Always, <i>n</i> (%)	94 (0.2)	<10 (<x%)	92 (0.2)
Missing, <i>n</i>	10,908	275	10,633
Functional health literacy			
High, <i>n</i> (%)	34,077 (75.5)	648 (73.6)	33,429 (75.5)
Low, <i>n</i> (%)	11,087 (24.5)	233 (26.4)	10,854 (24.5)
Missing, <i>n</i>	10,920	275	10,645
Communicative HL			
Talk other people problems complaints			
Never, <i>n</i> (%)	9,888 (21.9)	136 (15.4)	9,752 (22.0)
Occasionally, <i>n</i> (%)	14,922 (33.0)	297 (33.7)	14,625 (33.0)
Sometimes, <i>n</i> (%)	12,294 (27.2)	263 (29.9)	12,031 (27.2)
Often, <i>n</i> (%)	6,237 (13.8)	134 (15.2)	6,103 (13.8)
Always, <i>n</i> (%)	1,829 (4.0)	51 (5.8)	1,778 (4.0)
Missing, <i>n</i>	10,914	275	10,639

Table 1 (continued)

	Total, n (%) (n = 56,084)	HS group, n (%) (n = 1,156)	Non-HS group, n (%) (n = 54,928)
Collect information problems/complaints			
Never, n (%)	10,438 (23.1)	150 (17.0)	10,288 (23.2)
Occasionally, n (%)	9,774 (21.6)	190 (21.6)	9,584 (21.6)
Sometimes, n (%)	8,767 (19.4)	173 (19.6)	8,594 (19.4)
Often, n (%)	10,676 (23.6)	239 (27.1)	10,437 (23.6)
Always, n (%)	5,505 (12.2)	129 (14.6)	5,376 (12.1)
Missing, n	10,924	275	10,649
Critical HL			
Collect information to be able decisions			
Never, n (%)	7,184 (15.9)	103 (11.7)	7,081 (16.0)
Occasionally, n (%)	10,247 (22.7)	176 (20.0)	10,071 (22.7)
Sometimes, n (%)	9,687 (21.4)	185 (21.0)	9,502 (21.5)
Often, n (%)	11,175 (24.7)	264 (30.0)	10,911 (24.6)
Always, n (%)	6,880 (15.2)	153 (17.4)	6,727 (15.2)
Missing, n	10,911	275	10,636

HS, hidradenitis suppurativa; HL, health literacy; BMI, body mass index; IQR, interquartile range; NR, not reported.

Results

Study Population

A total of 56,084 adult respondents were included in the study, of whom 60% were female. The mean age was 56 years (Table 1). Within the overall study population, 2.1% reported a (self-) diagnosis of HS and were consequently classified into the HS cohort. Compared to the non-HS cohort, the HS cohort ($n = 1,156$) was younger and more often female, had a higher BMI as well as a lower socioeconomic status, as published previously (online suppl. Table 1) [23].

Functional Health Literacy

Among the 1,156 participants with HS, a prevalence of limited functional health literacy was identified in 26.4%. The overall prevalence of limited functional health literacy in the non-HS cohort was 24.5%. Limited health literacy was more prevalent among HS patients compared to the non-HS group, although this difference was not significant. Within the HS cohort, 6.9% of the participants reported “sometimes,” “often,” or “always” requiring help with reading information materials from the hospital or another healthcare provider. Furthermore, 15.8% reported feeling “not at all,” “a little bit,” or “somewhat” confident when filling out medical forms, and 11.5% reported “sometimes,” “often,” or “always” experiencing trouble understanding their medical situation because of difficulty with written information.

Communicative Health Literacy

Within the HS cohort, 49.1% of the participants “never” or “only occasionally” talk to other people about their problems or complaints for which they receive help or treatment. Considering the collection of information about their problems or concerns, 38.6% of the HS cohort reported “never” or only “occasionally” undertake such action. Regarding communicative health literacy, the HS group is not inferior to the controls, who showed percentages of 55.0% and 44.8%, respectively.

Critical Health Literacy

Within the HS cohort, 31.7% of the individuals reported either “never” or “occasionally” collecting information to make decisions related to their health, compared to 38.7% in the control group.

Association between Health Literacy and Patient Characteristics

Within the HS cohort, logistic regression analyses were performed to examine the association between limited and adequate functional health literacy. Univariate analysis showed that limited functional health literacy was associated with higher BMI (26.9 versus 25.8 kg/m²) (OR = 0.957 [0.931–0.984], $p = 0.002$), lower education level (34.5% versus 19.9%) (OR = 0.472 [0.338–0.659], $p < 0.001$), lower socioeconomic status (−0.68 versus −0.58) (OR = 1.186 [1.024–1.374],

Table 2. Logistic regression analysis in the HS cohort between limited and adequate health literacy

	Adequate health literacy (n = 648)	Limited health literacy (n = 233)	p value	Crude OR (95% CI)	p value	Adjusted OR ^a (95% CI)
Sex, n (%)						
Female	476 (73.5)	172 (73.8)	0.914	0.981		
Male	172 (26.5)	61 (26.2)		[0.698–1.379]		
HS diagnosis, n (%)						
Diagnosis	239 (36.9)	93 (39.9)	0.413	0.880		
Self-reported	409 (63.1)	140 (60.1)		[0.647–1.196]		
Age, median [IQR], years	52.0 [44.0–59.0]	54.0 [46.0–60.5]	0.286	0.993		
				[0.980–1.006]		
Smoking status						
Non smokers, n (%)	201 (37.6)	61 (33.3)	0.297	1.207		
				[0.848–1.719]		
Current, n (%)	155 (29.0)	67 (36.6)	0.056	0.708		
				[0.497–1.009]		
Ex-smokers, n (%)	178 (33.3)	55 (30.1)	0.414	1.164		
				[0.809–1.674]		
Missing, n	114	50				
BMI, median [IQR]	25.8 [23.4–29.1]	26.9 [24.1–30.9]	0.002	0.957	0.034	0.969
				[0.931–0.984]		[0.941–0.998]
Age of onset median [IQR], years	25.0 [18.0–40.0]	25.0 [17.3–40.0]	0.983	1.000		
				[0.991–1.010]		
Education						
Low, n (%)	127 (19.9)	79 (34.5)	<0.001	0.472	<0.001	0.495
				[0.338–0.659]		[0.350–0.701]
Medium, n (%)	272 (42.6)	112 (48.9)	0.101	0.776		
				[0.573–1.051]		
High, n (%)	239 (37.5)	38 (16.6)	<0.001	3.011	<0.001	2.897
				[2.052–4.417]		[1.971–4.258]
Missing, n	10	4				
Socioeconomic status, median [IQR]	–0.58 [–1.25 to +0.13]	–0.68 [–1.30 to –0.15]	0.023	1.186	0.020	1.194
				[1.024–1.374]		[1.029–1.386]
Missing, n	78	22				
Hurley stage						
Hurley I, n (%)	475 (74.2)	150 (67.0)	0.037	1.420	0.047	1.400
				[1.021–1.975]		[1.005–1.952]
Hurley II–III, n (%)	165 (25.8)	74 (33.0)				
Missing, n	8	9				

HS, hidradenitis suppurativa; BMI, body mass index; IQR, interquartile range; OR, odds ratio. ^aAdjusted for sex, age, BMI.

$p = 0.023$), and higher prevalence of Hurley II or III stage of disease (33.0% versus 25.8%) (OR = 1.420 [1.021–1.975], $p = 0.037$) (Table 2). Adequate health literacy was positively associated with a higher education level (37.5% versus 16.6%) (OR = 3.011 [2.052–4.417], $p < 0.001$). Educational level, socioeconomic status, and Hurley stage remained significant in the multivariate logistic regression after adjusting for age, sex, and BMI.

Discussion

This extensive epidemiological study in the Northern Netherlands revealed that more than a quarter of the HS patients encounter limited health literacy (Fig. 1). Limited health literacy was more prevalent among the HS group compared to the non-HS group, although not significant. In the management of HS, written materials about the disease and treatment options are frequently used. Our

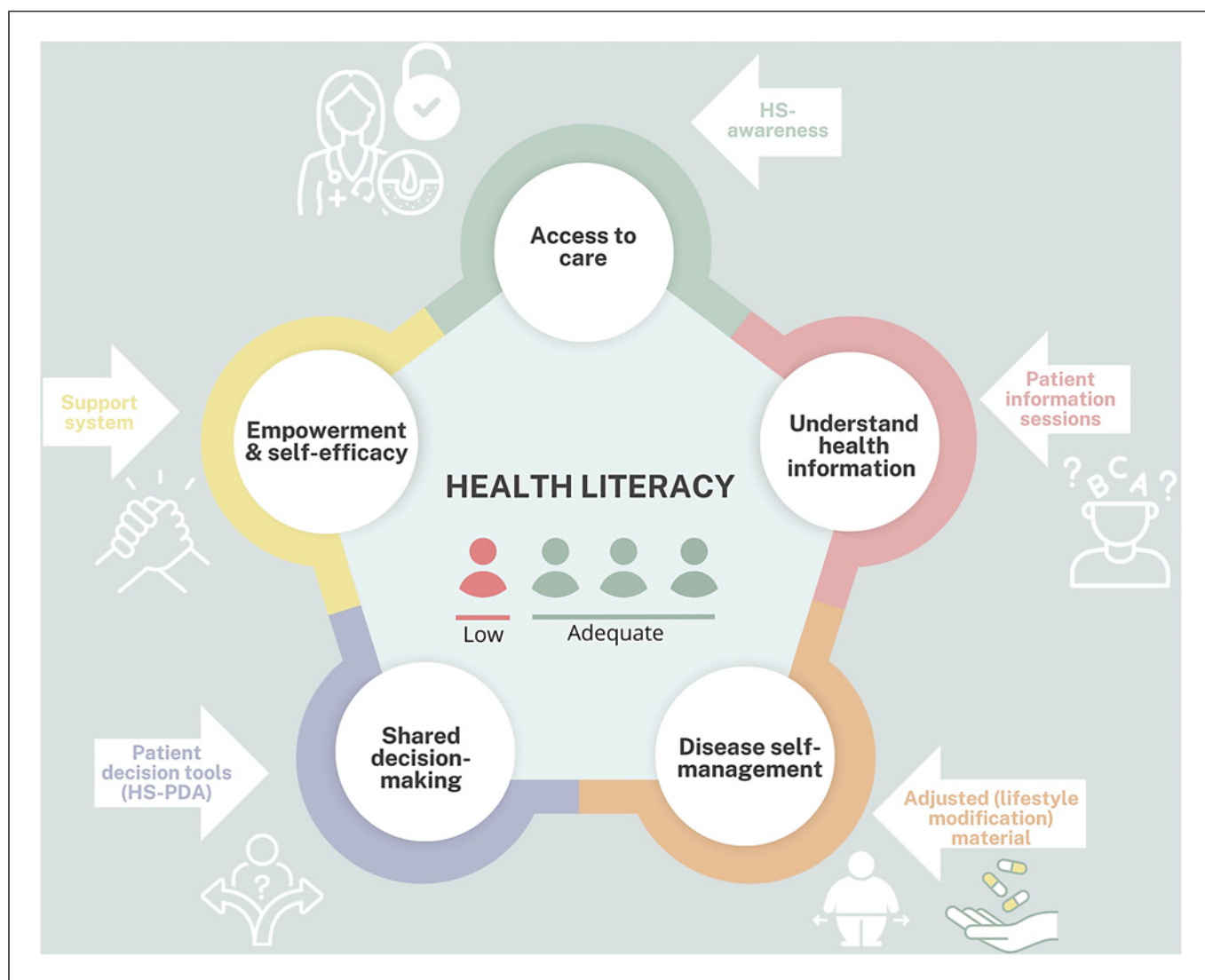


Fig. 1. Health literacy among patients with HS.

research demonstrated that 11.5% of the HS patients indicated experiencing occasional, frequent, or consistent difficulties in comprehending their medical condition due to challenges with written information. Furthermore, nearly half of the HS patients reported either never or occasionally discussing their condition with others. These findings suggest that a significant part of the HS patients is susceptible to poorer health due to limited health literacy, as limited health literacy is associated with inadequate and ineffective use of healthcare, increased health costs, and disparities in health. Patients with lower health literacy frequently exhibit reduced comprehension of health-related information and their medical condition, as well as lower medication adherence [10, 13, 33].

Low socioeconomic status, particularly low educational attainment, is considered the primary determinant of limited health literacy [13]. Our study confirmed this in HS as an association between limited health literacy and low educational level and low socioeconomic status was found in our cohort. Moreover, this indicates the importance of unravelling other risk factors for limited health literacy among HS patients.

Limited health literacy showed a positive association with higher BMI after adjusting for sex and age. Obesity is a known risk factor for HS, also confirmed in our study by the significantly higher BMI (mean: 26.4 kg/m²) in the HS cohort, compared to the non-HS cohort. Obesity contributes to higher morbidity and mortality and is a

significant risk factor for cardiovascular disease, diabetes, cancer, liver and kidney disease, and depression, to name a few [34–38]. Within the HS cohort, individuals with limited health literacy displayed significantly higher BMI compared to those with adequate health literacy. Lifestyle modifications, such as weight loss and reduction of skin friction, hold a significant place in the treatment of HS [39, 40]. Our current study showed that it is crucial to be aware of this particular target population with limited health literacy when developing or adjusting lifestyle modification materials and educational modules to ensure that this information effectively reaches the right individuals.

Limited health literacy demonstrated a positive association with advanced disease stage, after adjusting for sex, BMI, and age as these patients significantly had a higher prevalence of Hurley II or III stage of the disease. This implies a potential influence of health literacy on disease progression. A link between limited health literacy and higher disease severity has been established in other chronic conditions, such as COPD and diabetes, possibly attributed to refraining from early interventions due to limited knowledge [41, 42]. Early interventions include implementing lifestyle modifications, adhering to medication, and seeking appropriate support, which might prevent disease progression. Alternatively, the debilitating nature of the disease could restrict patients, for example, in their educational achievement, leading to limited health literacy.

Patients with limited health literacy frequently encounter obstacles in acquiring the necessary skills and knowledge for effective self-management, which is essential in chronic diseases to prevent disease progression and complications [10, 43]. Jager et al. [44] demonstrated that patients with limited health literacy and chronic diseases often experience lack of person-centred care, as excessive text and information overload hinder comprehension. This is further supported by the fact that 11.4% of patients indicated they “sometimes,” “often,” or “always” struggle to understand their medical situation, and 38.6% reported that they “never” or “occasionally” gather information about their problems or complaints. Hence, clear and uniform information is essential, preferably supported by graphic illustrations and images. Additionally, patient information sessions should be considered to improve patient’s knowledge of their ailment and treatment options [45]. Furthermore, a dedicated support system is important for enabling these patients to attain motivation, establish and sustain positive behaviour, and increase self-management. These

insights can be applied to the enhancement of HS care in the future.

In addition to self-management, shared decision-making is another challenge in patients with limited health literacy. Throughout the shared decision-making process, all three levels of health literacy skills (functional, communicative, and critical) are required to effectively engage with healthcare professionals [15, 16, 39, 46]. Muscat et al. have illustrated that health literacy skills for shared decision-making can evolve and enhance through education and training [47]. Particularly for HS patients with limited health literacy, tools are important to facilitate informed decision-making. Patient decision tools (PDAs) are tools that facilitate informed shared decision-making between patients and healthcare providers, such as the HS-PDA [20]. We highly encourage further development in this field.

This population-based study is the first study to explore health literacy in patients with HS. Strengths include the large sample size and the use of a validated health literacy score. Limitations of this study include selection bias, which could lead to an underestimation of the proportion of HS patients with limited health literacy, the use of self-reported questionnaires for HS diagnosis, and the low numbers of patients with Hurley II or III stage of the disease. The low quantity of patients with Hurley II or III stage of the disease could explain the lack of significance of health literacy levels between patients with HS and the control group. Additionally, this current study was conducted in a population in the Northern part of the Netherlands, in a region which is known to have an overall lower socioeconomic status. This may have affected the lack of significance between the HS group and the controls [48]. Therefore, for future research, we recommend conducting similar studies in various geographical distributions.

Conclusions

Our study highlights the importance of addressing health literacy within HS patients, given the high prevalence of limited health literacy and its positive associations with higher BMI and more severe disease stages. Future research should focus on further identifying health literacy in the HS population, including the use of other health literacy questionnaires, and exploring interventions aimed at improving health literacy in this specific group. This effort is essential for enhancing patient-centred care in HS.

Statement of Ethics

All participants provided written informed consent. The study protocol was reviewed and approved by the University Medical Center Groningen (UMCG) Medical Ethical Committee, Approval No. 2007/152.

Conflict of Interest Statement

N.D.K. Koerts reports no conflicts of interest. B. Horváth reports fees from Janssen-Cilag (advisory boards, educational grants, consultations, investigator initiative studies), AbbVie (advisory boards, educational grants, consultations, investigator initiative studies), Novartis Pharma (advisory Boards, consultations, investigator initiative studies), UCB Pharma (advisory boards, consultations), Leo Pharma (consultations), Solenne B.V. (investigator initiative studies), Celgene (consultations, investigator initiative studies), Akari Therapeutics (consultations, investigator initiative studies), Philips (consultation), Roche (consultation), Regeneron (consultation), and Sanofi (consultation). All contracts are reviewed and signed by the Board of Directors, and all fees were paid to the institution.

Funding Sources

The Lifelines initiative has been made possible by subsidy from the Dutch Ministry of Health, Welfare and Sport, the Dutch Ministry of Economic Affairs, the University Medical Center Groningen (UMCG), Groningen University and the Provinces in the North of the Netherlands (Drenthe, Friesland, Groningen).

Author Contributions

Nicole D.K. Koerts: conceptualization (equal), writing – original draft (lead), formal analysis (lead), and writing – review and editing (equal). Barbara Horváth: conceptualization (equal), writing – review and editing (equal), and supervision (lead).

Data Availability Statement

Data may be obtained from a third party and are not publicly available. Researchers can apply to use the Lifelines data used in this study. More information about how to request Lifelines data and the conditions of use can be found on their website (<https://www.lifelines-biobank.com/researchers/working-with-us>).

References

- 1 Sabat R, Jemec GBE, Matusiak Ł, Kimball AB, Prens E, Wolk K. Hidradenitis suppurativa. *Nat Rev Dis Primers*. 2020;6(1):18. <https://doi.org/10.1038/s41572-020-0149-1>
- 2 Zouboulis CC, Del Marmol V, Mrowietz U, Prens EP, Tzellos T, Jemec GBE. Hidradenitis suppurativa/acne inversa: criteria for diagnosis, severity assessment, classification and disease evaluation. *Dermatology*. 2015; 231(2):184–90. <https://doi.org/10.1159/000431175>
- 3 Ingram JR, Bettoli V, Espy JJ, Kokolakis G, Martorell A, Villani AP, et al. Unmet clinical needs and burden of disease in hidradenitis suppurativa: real-world experience from EU5 and US. *J Eur Acad Dermatol Venereol*. 2022; 36(9):1597–605. <https://doi.org/10.1111/jdv.18163>
- 4 Garg A, Neuren E, Cha D, Kirby JS, Ingram JR, Jemec GBE, et al. Evaluating patients' unmet needs in hidradenitis suppurativa: results from the global survey of impact and healthcare needs (VOICE) project. *J Am Acad Dermatol*. 2020;82(2):366–76. <https://doi.org/10.1016/j.jaad.2019.06.1301>
- 5 Esmann S, Jemec GB. Psychosocial impact of hidradenitis suppurativa: a qualitative study. *Acta Derm Venereol*. 2011;91(3):328–32. <https://doi.org/10.2340/00015555-1082>
- 6 Nguyen TV, Damiani G, Orenstein LAV, Hamzavi I, Jemec GB. Hidradenitis suppurativa: an update on epidemiology, phenotypes, diagnosis, pathogenesis, comorbidities and quality of life. *J Eur Acad Dermatol Venereol*. 2021;35(1):50–61. <https://doi.org/10.1111/jdv.16677>
- 7 Saunte DM, Boer J, Stratigos A, Szepletowski JC, Hamzavi I, Kim KH, et al. Diagnostic delay in hidradenitis suppurativa is a global problem. *Br J Dermatol*. 2015; 173(6):1546–9. <https://doi.org/10.1111/bjd.14038>
- 8 Thompson AG. The meaning of patient involvement and participation in health care consultations: a taxonomy. *Soc Sci Med*. 2007;64(6):1297–310. <https://doi.org/10.1016/j.socscimed.2006.11.002>
- 9 Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns*. 2002; 48(2):177–87. [https://doi.org/10.1016/s0738-3991\(02\)00032-0](https://doi.org/10.1016/s0738-3991(02)00032-0)
- 10 van der Gaag M, Heijmans M, Spoiala C, Rademakers J. The importance of health literacy for self-management: a scoping review of reviews. *Chronic Illn*. 2022;18(2): 234–54. <https://doi.org/10.1177/17423953211035472>
- 11 van der Heide I, Heijmans M, Schuit AJ, Uiters E, Rademakers J. Functional, interactive and critical health literacy: varying relationships with control over care and number of GP visits. *Patient Educ Couns*. 2015;98(8):998–1004. <https://doi.org/10.1016/j.pec.2015.04.006>
- 12 Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med*. 2011;155(2):97–107. <https://doi.org/10.7326/0003-4819-155-2-201107190-00005>
- 13 Coughlin SS, Vernon M, Hatzigeorgiou C, George V. Health literacy, social determinants of health, and disease prevention and control. *J Environ Health Sci*. 2020;6(1): 3061.
- 14 Urstad KH, Andersen MH, Larsen MH, Borge CR, Helseth S, Wahl AK. Definitions and measurement of health literacy in health and medicine research: a systematic review. *BMJ Open*. 2022;12(2):e056294. <https://doi.org/10.1136/bmjopen-2021-056294>
- 15 Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promot Int*. 2000; 15(3):259–67. <https://doi.org/10.1093/heapro/15.3.259>
- 16 Heijmans M, Waverijn G, Rademakers J, van der Vaart R, Rijken M. Functional, communicative and critical health literacy of chronic disease patients and their importance for self-management. *Patient Educ Couns*. 2015;98(1):41–8. <https://doi.org/10.1016/j.pec.2014.10.006>
- 17 White S, Chen J, Atchison R. Relationship of preventive health practices and health literacy: a national study. *Am J Health Behav*. 2008;32(3):227–42. <https://doi.org/10.5555/ajhb.2008.32.3.227>

- 18 Baker DW, Wolf MS, Feinglass J, Thompson JA. Health literacy, cognitive abilities, and mortality among elderly persons. *J Gen Intern Med*. 2008;23(6):723–6. <https://doi.org/10.1007/s11606-008-0566-4>
- 19 Kripalani S, Henderson LE, Chiu EY, Robertson R, Kolm P, Jacobson TA. Predictors of medication self-management skill in a low-literacy population. *J Gen Intern Med*. 2006; 21(8):852–6. <https://doi.org/10.1111/j.1525-1497.2006.00536.x>
- 20 McBride O, McLean D, Samardzic T, Yannuzzi C, Guibault S, Sayed C, et al. Development of a hidradenitis suppurativa patient decision aid. *Dermatol Online J*. 2020;26(11): 13030/qt18p1n8tt. <https://doi.org/10.5070/d32611047214>
- 21 McLean D, McBride O, Samardzic T, Sisic M, Dellavalle RP, Tan J. Impact of a hidradenitis suppurativa patient decision aid on treatment decision making: a randomized controlled trial. *JAAD Int*. 2020;1(2):190–9. <https://doi.org/10.1016/j.jdin.2020.09.001>
- 22 Deckers IE, Janse IC, van der Zee HH, Nijsten T, Boer J, Horváth B, et al. Hidradenitis suppurativa (HS) is associated with low socioeconomic status (SES): a cross-sectional reference study. *J Am Acad Dermatol*. 2016; 75(4):755–9.e1. <https://doi.org/10.1016/j.jaad.2016.04.067>
- 23 Prens LM, Bouwman K, Troelstra LD, Prens EP, Alizadeh BZ, Horváth B. New insights in hidradenitis suppurativa from a population-based Dutch cohort: prevalence, smoking behaviour, socioeconomic status and comorbidities. *Br J Dermatol*. 2022;186(5): 814–22. <https://doi.org/10.1111/bjd.20954>
- 24 Stormacq C, Van den Broucke S, Wosinski J. Does health literacy mediate the relationship between socioeconomic status and health disparities? Integrative review. *Health Promot Int*. 2019;34(5):e1–17. <https://doi.org/10.1093/heapro/day062>
- 25 Sijtsma A, Rienks J, van der Harst P, Navis G, Rosmalen JG, Dotinga A. Cohort Profile Update: Lifelines, a three-generation cohort study and biobank. *Int J Epidemiol*. 2022; 51(5):e295–302. <https://doi.org/10.1093/ije/dyab257>
- 26 Esmann S, Dufour DN, Jemec GBE. Questionnaire-based diagnosis of hidradenitis suppurativa: specificity, sensitivity and positive predictive value of specific diagnostic questions. *Br J Dermatol*. 2010; 163(1):102–6. <https://doi.org/10.1111/j.1365-2133.2010.09773.x>
- 27 Vinding GR, Miller IM, Zarchi K, Ibler KS, Ellervik C, Jemec GBE. The prevalence of inverse recurrent suppuration: a population-based study of possible hidradenitis suppurativa. *Br J Dermatol*. 2014;170(4):884–9. <https://doi.org/10.1111/bjd.12787>
- 28 Chew LD, Griffin JM, Partin MR, Noorbaloochi S, Grill JP, Snyder A, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med*. 2008;23(5):561–6. <https://doi.org/10.1007/s11606-008-0520-5>
- 29 Sørensen K, Pelikan JM, Röthlin F, Ganahl K, Slonska Z, Doyle G, et al. Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *Eur J Public Health*. 2015;25(6):1053–8. <https://doi.org/10.1093/eurpub/ckv043>
- 30 van der Vaart R, Drossaert CH, Taal E, ten Klooster PM, Hilderink-Koertshuis RT, Klaase JM, et al. Validation of the Dutch functional, communicative and critical health literacy scales. *Patient Educ Couns*. 2012; 89(1):82–8. <https://doi.org/10.1016/j.pec.2012.07.014>
- 31 Centraal Bureau voor de Statistiek. Well-being not distributed equally. New York: CBS; 2018. Available from: <https://www.cbs.nl/en-gb/news/2018/20/well-being-not-distributed-equally/education-level>
- 32 IBM Corp. IBM SPSS statistics for windows, version 28.0. Armonk, NY: IBM Corp; 2021.
- 33 Liu C, Wang D, Liu C, Jiang J, Wang X, Chen H, et al. What is the meaning of health literacy? A systematic review and qualitative synthesis. *Fam Med Community Health*. 2020;8(2):e000351. <https://doi.org/10.1136/fmch-2020-000351>
- 34 Powell-Wiley TM, Poirier P, Burke LE, Després JP, Gordon-Larsen P, Lavie CJ, et al. Obesity and cardiovascular disease: a scientific statement from the American heart association. *Circulation*. 2021;143(21):e984–1010. <https://doi.org/10.1161/CIR.0000000000000973>
- 35 Pati S, Irfan W, Jameel A, Ahmed S, Shahid RK. Obesity and cancer: a current overview of epidemiology, pathogenesis, outcomes, and management. *Cancers*. 2023;15(2):485. <https://doi.org/10.3390/cancers15020485>
- 36 Fabbrini E, Sullivan S, Klein S. Obesity and nonalcoholic fatty liver disease: biochemical, metabolic, and clinical implications. *Hepatology*. 2010;51(2):679–89. <https://doi.org/10.1002/hep.23280>
- 37 Prasad R, Jha RK, Keerti A. Chronic kidney disease: its relationship with obesity. *Cureus*. 2022;14(10):e30535. <https://doi.org/10.7759/cureus.30535>
- 38 Blasco BV, García-Jiménez J, Bodoano I, Gutiérrez-Rojas L. Obesity and depression: its prevalence and influence as a prognostic factor: a systematic review. *Psychiatry Investig*. 2020;17(8):715–24. <https://doi.org/10.30773/pi.2020.0099>
- 39 Macklis PC, Tyler K, Kaffenberger J, Kwatra S, Kaffenberger BH. Lifestyle modifications associated with symptom improvement in hidradenitis suppurativa patients. *Arch Dermatol Res*. 2022;314(3):293–300. <https://doi.org/10.1007/s00403-021-02233-y>
- 40 Weber I, Giefer J, Martin KL. Effects of exercise and dietary modifications on hidradenitis suppurativa: a systematic review. *Am J Clin Dermatol*. 2023;24(3):343–57. <https://doi.org/10.1007/s40257-023-00756-w>
- 41 Caruso R, Magon A, Baroni I, Dellafiore F, Arrigoni C, Pittella F, et al. Health literacy in type 2 diabetes patients: a systematic review of systematic reviews. *Acta Diabetol*. 2018;55: 1–12. <https://doi.org/10.1007/s00592-017-1071-1>
- 42 Azkan Ture D, Bhattacharya S, Demirci H, Yildiz T. Health literacy and health outcomes in chronic obstructive pulmonary disease patients: An explorative study. *Front Public Health*. 2022;10:846768. <https://doi.org/10.3389/fpubh.2022.846768>
- 43 Dinh TTH, Bonner A. Exploring the relationships between health literacy, social support, self-efficacy and self-management in adults with multiple chronic diseases. *BMC Health Serv Res*. 2023;23(1):923. <https://doi.org/10.1186/s12913-023-09907-5>
- 44 Jager M, de Zeeuw J, Tullius J, Papa R, Giammarchi C, Whittal A, et al. Patient perspectives to inform a health literacy educational program: a systematic review and thematic synthesis of qualitative studies. *Int J Environ Res Public Health*. 2019; 16(21):4300. <https://doi.org/10.3390/ijerph16214300>
- 45 Prussick L, Tonelli S, Gottlieb AB, Joshupura D, Alomran A, Zancanaro P, et al. Improving health literacy and treatment understanding of hidradenitis suppurativa using group educational interventions. *J Dermatolog Treat*. 2019;30(7):708–13. <https://doi.org/10.1080/09546634.2018.1562536>
- 46 Smith SK, Nutbeam D, McCaffery KJ. Insights into the concept and measurement of health literacy from a study of shared decision-making in a low literacy population. *J Health Psychol*. 2013;18(8):1011–22. <https://doi.org/10.1177/1359105312468192>
- 47 Muscat DM, Shepherd HL, Nutbeam D, Morony S, Smith SK, Dhillion NM, et al. Developing verbal health literacy with adult learners through training in shared decision-making. *Health Lit Res Pract*. 2017;1(4): e257–68. <https://doi.org/10.3928/24748307-20171208-02>
- 48 Sociaaleconomische status|Volksgezondheid en Zorg. Available from: <https://www.vzinfo.nl/sociaaleconomische-status>